

**STATE COUNCIL FOR PERSONS WITH DISABILITIES  
BRAIN INJURY COMMITTEE  
February 5, 2018 – 2:00 PM  
Smyrna Rest Area, Smyrna**

**PRESENT:** Ann Phillips, Chair; Linda Brittingham, CCHS; Sybil Brown (for Wendy Strauss), GACEC; Thomas Cairo, Bayhealth Neurosurgery; Vanessa Deloach (for Rick Komalski), DDDS; Donna Dixon, Bayhealth Neurosurgery; Debbie Dunlap, Advocate; Katie Freeman (for Susan Cczyk), PBHS; Kristen Harvey (for Barbara Monaghan), DDC; Michelle Hood, St. Francis LIFE; Dale Matusевич (for Mary Ann Mieczkowski), DOE; Ron Sarg, DCVA/MOAA; Jamila Waigwa (for Dava Newman), DSAAPD; Laura Waterland (via phone), Community Legal Aide; and Amber Rivard, Support Staff.

**CALL TO ORDER**

Ann called the meeting to order at 2:08pm.

**ADDITIONS/DELETIONS TO THE AGENDA**

None

**APPROVAL OF MINUTES**

Vanessa motioned for approval of the December minutes. Ron seconded the motion. The December 4, 2017 minutes were approved as submitted.

**BUSINESS**

Follow-Up- DHIN (Delaware Healthy Information Network)

Ann stated that a subcommittee and costs for the DHIN subcommittee was previously discussed. John had commented from the December meeting that he discussed with DHIN representatives on organizing a small subcommittee group. He added that there was discussion on costs of utilizing DHIN services and that he would find out more information on the limited budget from BIC. John recently found that he had leftover funding from last year that could be utilized based on what BIC wants from DHIN. John volunteered to liaison with the JFC for funding. Working with DHIN will require funding. Thomas added that DHIN has a multitude of information and the subcommittee's purpose is to decipher what, where and how to have data that is beneficial to BIC. People have shown interest in joining the subcommittee. Ann questioned whether we need another subcommittee or if members wanted to continue to discuss this during the BIC meetings because she would feel better knowing everyone had input without asking anyone to give another hour of their time separate from here. Thomas stated that we are trying to make as comprehensive of a list of individuals that are living with brain injury. Ann stated that the other discussions from this meeting could tie in to the DHIN discussion.

Funding for BIC

John commented that the funding does not have to come out from SCPD and the funding could come from other groups represented at the table. Public Health and Title V stated that there is supposed to be funding for BIC. There was clarification on contacting the representative from

Public Health to discuss about the funding (Leah Woodall, Deputy Director). Ann volunteered to send the Director of Public Health an email reminding them of having an active representative for Public Health. She added that if there is a representative from Medicaid in the Committee that he or she could provide the Committee with data on how much funding is needed. John stated that he will look into it. Ann stated the Committee will keep coming back to these discussions in future meetings.

### Google Groups

Thomas stated that from the previous meeting that the Committee was deciding on which three were the most appropriate to use. There is a support system for the Google groups and needing an owner for operating the support system. The owner of the group would need to be the administrative keeper and there could be authorized members to do it on the owner's behalf. Ann added that this could be something BIC needs to fund due to it being lot of work and have someone that it is time-consuming. Thomas asked for clarification on who is the one to add or delete members of the Committee so as to not have excess usage of Google Groups. John clarified that SCPD is in charge of that. SCPD would be the main owner of the Google Groups and it could rotate through every member. Ann asked is it just for the Committee to use as better communication. Thomas clarified that it is just for Committee members only. Ann volunteered to start the Google Groups process and assign others with assisting her for the groups in sharing information on brain injury. Thomas commented that there is an initial setup process that needs to get done and he will assist Ann in setting up the groups with the gathered information. Thomas volunteered to setup a demonstration in how to use the Google Groups for BIC. Google Groups will assist in Committee becoming more organized in what their Strategic Planning Goals and Objectives are for this upcoming year and with emails. Thomas will email John with information for the Google Groups and Ann provided her email to assist in this process. Ann asked if there is a cost for using Google Groups. Thomas clarified that it is free of cost.

### Legislative Priorities

Kristen stated that the DDC helped organize the planning and oversight of the legislative priorities. If anyone has any questions on the priorities, they can check the DDC website: <https://ddc.delaware.gov/> or contact Kristen Harvey. It is also on the SCPD website: <https://scpd.delaware.gov/>

John reviewed the list of priorities. It is a collaborative effort in combining both councils and self-advocates and it was agreed upon by the legislation. There was something on brain injury, but it was not voted into the priorities of the legislation.

### Needs Assessment (2007)

Ann stated that in the back of the Needs Assessment packet, there was a copy of part of the assessment. In the assessment packet was a survey with questions that were asked, a summary of the answers and information on the Delaware Trauma Registry. During the November or December 2017 meeting, it was discussed on what kind of questions were asked to service providers and the services or training they offered. It was summarized in the packet along with how many surveys were sent out, number of people that received the surveys and the results of the answered questions. Partial of the reason for the Needs Assessment was for the Committee to look according to the strategic plan for what might be able to blend into the goals and objectives of the Committee. Nothing has been done with the assessment ever since 2007.

Recommendations were found on page one (1) of the handout in the Executive Summary based on the analyses of the surveys. Most of the recommendations were on improving the data collection system and service delivery for individuals with traumatic brain injury (TBI). The recommendations were as follows:

- Develop one common TBI registry that is used by all agencies and hospitals to collect prevalence and incidence data for TBI.
- Correct outpatient discharge data for patients with mild TBI.
- Establish a database of TBI-specific services and eligibility requirements of existing services.
- Establish continuous funding streams to support brain injury treatment and rehabilitation.
- Establish and fund an in-patient/out-patient rehabilitation facility specific to the needs of TBI.
- Establish and fund adult day programs specific to the needs of individuals with TBI.
- Provide additional funding to state agencies serving individuals with TBI.
- Improve collaboration between service provider agencies.
- Provide additional trainings and educational opportunities for staff. The Brain Injury Association tried that recommendation at the Brain Injury Conference, but it was not successful.
- Investigate other states' registries and service delivery models for individuals with TBI. This recommendation is always changing. New Jersey provided the best model and different administration came in and the funding went away. This is the most difficult one to keep up. Ann suggested that the Committee could still look at models that were used.
- Explore and implement TBI prevention programs that reach individuals of all age groups, ethnicities, and in all counties.
- Implement a screening tool for children outside of the special education system who may have sustained a TBI.

Ann stated that they wanted to conduct a survivor and family survey, but there was no funding for it. She added that the bullet point for day care programs was more focused on adults with TBI that answered the surveys. There was a recommendation that was not added on training of educational staff to help identify children in a classroom setting if they have any changes (suspected of TBI). Ann and Thomas suggested that the committee needs to take a look at the Needs Assessment to see what information we can pull from it and then form the subcommittee to bring back to the committee as a whole for their approval any adjustments required prior to bringing DHIN back in.

Thomas asked how the data was grouped from the different ages of individuals with TBI. Ann stated that she will look into it. Thomas added that with DHIN providing so much information that the survey may not be necessary due to agencies providing information to DHIN already. There was clarification that the TBI data from the survey was from adults due to the children's schools not providing a good response and because all surveys were sent through regular mail (not email). The

surveys were an eye opener due to providers saying they provide services, but have no experience or training with brain injury.

The first goal under the first priority was to facilitate the ready availability of information on resources and services useful to persons with brain injury and their families. Thomas asked if the Committee could utilize the services that responded to the Needs Assessment Survey and contact them on the services that they provide to compile the list. Ann agreed with him and added that it would make it easier to see who in the Committee represents the agencies that participated in the surveys of the Needs Assessment. A comment was made that DHIN only collects certain types of data and SCPD data with DHIN data provide separate information. There is a concern of duplicates in information of DHIN, Medicaid and other agencies data on individuals with TBI with who will collect all the data. Ann clarified that a Public Health representative would be the one to collect the data, and Injury and Prevention worked with the Committee when they needed funding. Thomas added that DHIN would be a good place to start with collecting data or providing a list for individuals (age group) with TBI and where services for TBI are or are not located within an updated resource information. A suggestion was made to wait until meeting with DHIN to update the survey with what data they can or cannot collect. Another suggestion was made to form a subcommittee with DHIN for every member to provide as to the input and what questions should be asked in the updated survey.

Dale commented that another goal of the BIC Priorities, Goals and Objectives was improving state data collection system on individuals with brain injuries, their needs and services. He added that looking through the data, it sounds as if the Committee is unsure on the data that they want to collect. Before meeting with DHIN, Dale asked the Committee if they should look at what data does SCPD want to collect or are they starting from scratch with data we want to collect. A comment was made that it was discussed with DHIN before about what we want to collect and discussed about meeting with DHIN for a subcommittee discussion. A suggestion was made to not have a subcommittee and just keep discussing it as a topic for this Committee with every agencies' opinion at the table.

There has been discussion in opening it up to individuals that had a stroke to be included in the Needs Assessment. Individuals with a stroke have a wider range of services and could help the Committee gather more data information on what services are provided for them (on-going and short-term). Ann added that when JFC did that Medicaid Pilot Program, that the Committee discussed about the wording of the questions and JFC followed their input on how many individuals with types of brain injury that they had been missing. The more data on the different types that the Committee finds, the more we understand in needing funding for more services to assist those individuals. Questions were asked about what would be in the questionnaire and provide a resource survey. The survey was meant to help individuals and their families find services that are provided for specific brain injuries statewide.

Thomas added that prior to meeting with DHIN, the Committee should have a list of diagnosis relating to sustaining a brain injury and injury caused by traumas. We should Google search for a list of diagnosis TBI and other brain injuries. It could be reviewed at the next meeting to rehash over surveys and assessment packet. John added that we should think of what we want to accomplish when conducting survey and gathering data. Ann commented that that is why the survey was done and to show it to JFC to receive more funding for services that are lacking in assisting those with brain injuries. Amber will send a reminder two weeks ahead of time to electronically

resend the Assessment and the Priorities to the Committee. It was agreed that it should be a whole meeting to discuss about DHIN and the Assessment that go hand in hand with another.

#### DOE – Eligibility for TBI (Dale Matusevich)

Dale provided a summary handout of the Eligibility for TBI and what DOE currently is doing. DOE currently is reviewing their 925 regulations. Part of the 925 regulation is eligibility for criteria of each disability category in the State. There is a facilitator from University of Delaware (UD), Marika Ginsburg-Block, that facilitates the discussions so that DOE allows the Committee to provide input to discuss it more. It states that DOE is supposed to revise their regulations every four (4) years. There are thirteen (13) stakeholder groups around each disability category to gather input and will be posted for 60 days for Public Comment (approximately 3 meetings with each disability category). The handout that was provided by Dale explains what some of the current regulations are around. The bigger packet summarizes from every state on what is the TBI definition. Dale also had provided a worksheet on eligibility criteria for TBI comparing other states. The packet provides the State regulation and definition on TBI. Two questions were asked on the 925 regulation on individuals' eligibility for TBI (What challenges do IEPs face in determining eligibility for this category? After comparing federal to state criteria, and considering other supporting documents, what elements of the current eligibility criteria should be changed?). There is conflicting information in the report about how we are classifying TBI education. Dale asked if anyone had any input on the eligibility criteria for TBI.

A comment was made by Katie Freeman that children with acquired brain injuries have been getting overlooked and they had to be covered under another health impairment (disability category). New York and Ohio provide the children with eligibility to have TBI services. Thomas added that he is concerned for children with speech or language impairment that have those therapies but are not considered under TBI eligibility. Delaware had a lending option about substantially limiting Anti-Defamation League (ADL) that can have difficulty having children gaining eligibility. Ann added that the Committee discussion included verbal cuing that is needed for someone. Dale commented that part of the medical history is provided by parents that help with identifying a specific type of brain injury. Dale stated that if anyone has input on the eligibility for children with TBI for special education to contact him through email.

#### **ANNOUNCEMENTS**

None

#### **ADJOURNMENT**

The meeting adjourned at 4:03 pm.

Respectively submitted,

Amber Rivard  
SCPD Administrative Specialist